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Relationship Continuity and Person-Centred Care in How Spouses Make Sense of Challenging Care Needs

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Running head: Continuity and person-centred care

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Abstract

Objectives: Some spouses providing care for a partner with dementia experience continuity in the relationship: Despite the changes that have occurred, the person with dementia and the relationship are felt to be essentially the same as they were before the dementia. Others experience discontinuity: The person and the relationship feel very different. Previous qualitative research has suggested that continuity may be linked with the delivery of more person-centred care. Using a mixed-methods approach, the present study aimed to provide a more robust test of this claim.

Method: Twenty-six spousal carers completed the Birmingham Relationship Continuity Measure and the Caregiver Hassles Scale, and took part in an interview about their response to challenging care needs. Attributions about the causes of those needs were extracted from the interviews and coded. Codes referred either to dementia as a cause, or to a range of other causes that reflected a more person-centred focus. A measure of person-centred care was obtained by calculating the percentage of the total number of attributions that fell into these more person-centred categories.

Results: Consistent with the hypothesis that continuity and person-centred care are linked, those who reported greater continuity reported a significantly higher percentage of person-centred attributions.

Conclusions: Person-centred care is important for the well-being of those giving and those receiving the care. Little is currently known about how to support families to be more person-centred. The possibility of supporting person-centred care through enhancing the experience of continuity merits investigation.

Key words: dementia, family carer, relationship continuity, person-centred care, attributions

Relationship Continuity and Person-Centred Care in How Spouses Make Sense of Challenging Care Needs

Person-centred care (PCC) is widely advocated in many countries as an important guiding principle in the provision of care to those with dementia (Health Foundation, 2015; Paparella, 2016). It aligns with the prevailing ethical values of those countries and has beneficial outcomes for the well-being of both the person providing and the person receiving the care (Kim & Park, 2017). Brooker (2004) described four central components of PCC, summarised in the acronym *VIPS*. The *Valuing* component is about valuing the personhood of people with dementia and according them the same moral and social status as everyone else in society. The *Individual* component is about treating the person with dementia as an individual with a unique personal history and personality, and their own wishes, values and goals. The *Perspective* component refers to the need for the carer to try to understand the world from the perspective of the person with dementia, and to respond with empathy. The *Social* component is about creating a positive social environment and experience.

The concept of PCC is most often encountered in the context of carers employed in residential or hospital settings. In a systematic review Kim and Park (2017) reported that, although their inclusion criteria encompassed any carers in any setting, only two out of the 19 papers were carried out in the home setting and both of these focused on professional therapists rather than family carers. However, the concept of PCC has equal application to the provision of care by family members at home. In his original development of the concept, Kitwood (1993, 1997) drew inspiration from the work of Carl Rogers on the therapeutic relationship and conceptualised PCC in terms of the quality of the personal relationship between the carer and the person with dementia. Indeed, many have argued that the relational aspect of PCC should be made the primary focus and that we should aspire to

'relationship-centred' rather than person-centred care (Beach et al., 2006; Nolan, Davies, Brown, Keady, & Nolan, 2004). When considered as being essentially about the quality of the personal relationship between the care giver and the care receiver, the concept of PCC clearly has application in the family context (Nolan et al., 2004).

Promoting PCC in family settings is likely to have similar benefits to those reported in nursing and residential care settings. Understanding what promotes and what obstructs a person-centred approach to family care is therefore an important research objective. Given the essential connection between PCC and the relationship between the care giver and the care receiver, a relational perspective may be useful in furthering this understanding. One aspect of the relationship that has been linked in previous research to PCC is *relationship continuity-discontinuity*. This refers to the carer's experience of the relationship. In *continuity* the carer feels that the relationship and the person with dementia are essentially the same as the pre-dementia relationship and person, despite the changes that have occurred; in *discontinuity*, the other person and the relationship are experienced as being radically different (Riley et al., 2013; Riley, Evans, & Oyebode, 2018).

Several qualitative studies have suggested there may be a link between *continuity/ discontinuity* and aspects of PCC in spousal relationships. Lewis (1998) and Walters, Oyebode and Riley (2010) both suggested *discontinuity* is associated with a more controlling and restrictive style of caring (i.e. less *valuing* in terms of the VIPS framework). By contrast, *continuity* appears to be associated with a more tolerant and empathic response that takes the perspective of the person with dementia in trying to understand why they are behaving in that way (i.e. more *individual* and *perspective*) (Murray & Livingstone, 1998; Walters et al., 2010). It has also been suggested that *discontinuity* is associated with a more depersonalized and objectifying characterization of the person with dementia (i.e. less *individual*) (Chesla, Martinson, & Muwaswes, 1994; Walters et al., 2010).

In summary, the concept of PCC has rarely been applied to the provision of care and support by family members at home. However, promoting PCC in family settings is likely to have similar benefits to those reported in nursing and residential care settings. Understanding what promotes and what obstructs a person-centred approach to family care is therefore an important research objective. Given the centrality of relationships to the concept, a relational perspective may be useful in exploring its application to family care. Previous qualitative research involving spousal carers has suggested that an experience of *continuity* in the relationship may be linked to a more person-centred approach to care.

The present study aimed to provide a more robust test of this suggestion that *continuity* and PCC in the context of spousal relationships may be linked. The link has not been the primary focus of the qualitative studies described earlier: The suggestion of a link was incidental to the main topic and was not explored or justified in any depth. Moreover, although qualitative studies are valuable, the small number of participants involved and the subjectivity involved in the interpretation of the data can sometimes undermine confidence in the conclusions and make it difficult to draw general conclusions (Johnson & Onwuegbuzie, 2004). Corroborating the findings of qualitative studies with evidence from quantitative or mixed-methods studies can enhance generalizability and provide more robust conclusions (Johnson & Onwuegbuzie, 2004). The present study adopted a mixed-methods approach. Measures were taken of *continuity* and PCC in a sample of spousal carers. The measure of PCC was based on a mixed-methods approach; qualitative data were gathered in interviews and then converted into quantitative data. The hypothesis was that there would a significant correlation between the measures of *continuity* and PCC, with those showing more *continuity* also showing a more person-centred approach.

Method

Ethical approval was obtained through the UK's National Research Ethics Service (reference number 10/H0402/39). All participants provided written consent and none can be identified from this paper.

Participants

Sampling was non-random. Participants opted into the study after responding to a written invitation given to them by a range of health service or charitable organizations providing support services to carers, or to a presentation about the research given on the premises of the charitable organizations. Participants were required to be the spouse/partner and primary carer of someone with dementia who required substantial support with activities of daily living (i.e. support on a daily basis). They were required to be living with the person with dementia in the family home, and to have been in a relationship with that person for at least 10 years prior to the onset of the dementia. People were excluded if they were likely to have difficulty for whatever reason in completing questionnaires and taking part in an interview (e.g. insufficient grasp of English).

G*POWER (Faul, Erdfelder, Lang, & Buchner, 2007) was used to calculate the required sample size. The analysis involved correlations and a multiple regression analysis that tested the contribution of a single predictor variable. According to G*POWER, detection of a large correlation (r=.5), with an alpha set at .05 (two-tailed) and power at .80, requires a sample of 26. This was also adequate for detecting a large effect in the multiple regression.

Questionnaires

Each participant completed the Birmingham Relationship Continuity Measure (BRCM; Riley et al., 2013), an adapted version of the Caregiver Hassles Scale (CHS; Kinney & Stephens, 1989) and a semi-structured interview concerning care needs that they found challenging. The BRCM is a 23-item questionnaire designed to assess how the carer experiences their relationship with a spouse/partner with dementia. Higher scores indicate more *continuity*.

The original CHS is a 42-item questionnaire featuring events that may occur during day-to-day caring for someone with dementia. The purpose of its inclusion was to provide an idea of the level of care needs that the participants were dealing with, and to control for these needs in a multiple regression. The questionnaire asks whether an event has occurred within the past week, and to what extent it was considered a hassle. Only the first of these questions was asked in the present study because the interest was in the care needs of the person with dementia, not the carer's emotional reaction to them. The subscales include *assisting with basic activities of daily living* (e.g. toileting), *assisting with instrumental activities of daily living* (e.g. laundry), *cognitive status* (e.g. forgetfulness) and *behaviour* (e.g. wandering). Another subscale concerning the lack of social support was not included, again because the purpose of including the questionnaire was to obtain information about the care needs of the person with dementia. Higher scores indicate greater care needs.

As noted, one reason for including the CHS was to control for the care needs of the person with dementia in a multiple regression. *Continuity* may be more difficult to sustain in the face of certain kinds of care needs. Poveda, Osborne-Crowley, Laidlaw, Macleod and Power (2017) reported that *continuity* (as measured by the BRCM) was associated with lower scores on the Neuropsychiatric Inventory (which measures such things as disinhibition and agitation), but not with a measure of social cognition skills. It is also possible that challenging care needs such as those measured by the Neuropsychiatric Inventory make it more difficult to continue to provide a person-centred approach to the person being cared for. For example, it may be more difficult to maintain an empathic response when one is the victim of aggression (Bodley-Scott & Riley, 2015). This gives rise to a possible alternative explanation of any observed link between *continuity* and PCC: Rather than differences in *continuity* contributing to differences in PCC, it may be that any association between the two arises because both are influenced by the presence of certain care needs. The inclusion of the

CHS allowed an evaluation of this alternative explanation: If an observed correlation between *continuity* and PCC is a spurious one related to certain care needs, then one would expect any association between the two to diminish when variation in those needs is statistically controlled.

Measure of person-centred care: Data collection

Reflecting the lack of attention given to PCC in the family context, there were no quantitative measures of this variable available when the present study was carried out. Systematic reviews of measures of PCC have indicated that measures all relate to employed carers (with the exception of one measure published after completion of the present study) (Edvardsson & Innes, 2010; Martinez, Suarez-Alvarez, & Yanguas, 2016). These measures were not considered appropriate in the present context because many items do not apply in the family context. For example, the CARES measure of Gaugler, Hobday and Savik (2013) includes items concerning whether the carer introduces themselves to the person with dementia and makes a written record of the care episode.

It was necessary, therefore, to devise a way of measuring PCC in the family context. In doing this, it was decided to focus on the participants' understanding of particular behavioural changes in the person with dementia that they found stressful or difficult to manage. Understanding the behaviour of the person with dementia is an area in which differences in PCC may become apparent: It is influenced by the *perspective* component of PCC (i.e. understanding the situation from the perspective of the person with dementia) and the *individual* component (i.e. appreciating that the person is unique, with their own personal history etc.). The focus on behaviours that the participants experienced as stressful/difficult to manage was based on the consideration that they were likely to have given more thought to the reasons underlying such behaviours than behaviours that were less challenging.

Understanding the behaviour of others is the focus of attributional research. Again, there are no established quantitative measures of the attributions made by family carers about the behaviour of people with dementia. Instead, the present study used a mixed-methods approach based on the Leeds Attributional Coding System (Stratton, 1997). This has been widely adopted in attributional research: It is argued that it provides a measure that is more sensitive to the individual context in which the research is being conducted than a generic questionnaire (Stratton, 1997). The method involves extracting from semi-structured interviews participants' statements about their understanding of the causes of the behaviour of others, and then coding these statements into different categories of causal explanation. The frequency counts of the various codes can then be entered into statistical analysis. However, whereas most studies code the attributions using standard attributional categories (internal-external, controllable-uncontrollable etc.), the present study used an idiosyncratic set of codes that addressed the specific aims of the study. The aim was to obtain a measure of PCC and the standard codes provide no information relevant to this.

[Figure 1 about here]

Figure 1 provides a summary of the process involved in deriving the person-centred variable from the interview data. At the start of the interview, four common behavioural needs were described to the participants (sleep disturbance, wandering, repetitive questioning and behaviour that put the self or others at risk). These were selected because of their frequency and because they are reported to be among the more stressful situations to manage (Ward, Opie, & O'Connor, 2003) and therefore carers who experience them are more likely to have made an attempt to understand why they occur. Participants were asked to identify two of these that they experienced on a regular basis (at least once a month) and that they were willing to talk about. If they did not experience at least two on a regular basis, they were asked to identify one (or two) other behavioural needs that did occur at least once a

month, that they found challenging, and that they were willing to talk about. The reason for preferring them to select two of the four common behavioural changes was to try to minimise confounding that may arise because certain types of caring need may be more likely to be understood using certain categories of attribution (e.g. compared to low mood, hallucinations may be less frequently attributed to the person's personality). On the other hand, participants needed to talk about needs that they were regularly faced with; otherwise they were less likely to have developed detailed ideas about why they were occurring. In the event, two thirds of the needs that participants chose to speak about belonged to one of the four common needs that were described at the start of the interview.

Each participant was interviewed about the two care needs they had nominated in this way. For each situation, participants were asked to describe a recent occurrence of the behavioural need. They were asked why they thought their spouse was behaving in this way; what they found helpful as a way of managing the situation; why they thought this might be helpful; what did not help and why; and whether there were any other strategies they had tried in the past. The interviews were recorded and transcribed.

Measure of person-centred care: Coding process

To establish the coding system, transcripts of two interviews were examined and attributions about the two behaviours were extracted. An attribution was defined as a statement that explicitly stated or implicitly assumed some belief about why the behaviour was occurring. An initial list of ways of categorising these beliefs was drawn up. The categories were defined and a set of instructions (including fictional examples for each category) was drawn up for their application. Using these definitions and instructions, other members of the research team then coded the same two transcripts. These codings were then reviewed by the research team and further refinements made to clarify areas of uncertainty and ambiguity. Nine categories were established as shown in Table 1, which also provides

actual examples of the categories taken from the interviews. All attributions extracted from the interviews were then coded using these categories. For each participant, a frequency count was made of how many of their attributions fell into each category.

[Table 1 about here]

To obtain a measure of PCC, the categories in Table 1 were then divided into two groups: One group consisted of the *dementia-related* category (see Table 1 for an example) and the other of the remaining eight categories. These other eight categories were classed as *person-centred* categories in that, to a greater or lesser degree, they involved efforts to understand the behaviour from the perspective of the person with dementia (i.e. the *perspective* component of VIPS) and draw on knowledge of that person as an individual (i.e. the *individual* component). For example, *deep thought* (Table 1) is clearly an attempt to understand the behaviour from the perspective of the person with dementia; and *personality* clearly draws on knowledge of the person as an individual. The categories do vary in the degree to which they involve the *perspective* and *individual* components (e.g. compare the *deep* and *surface feelings* in Table 1). In general terms, however, it is difficult to argue that any of them definitely does not involve either of these components, and so they were all treated as providing some evidence of a more person-centred approach to understanding the behaviour.

The measure of person-centred care entered into the statistical analysis was the percentage of the total number of a participant's attributions that fell into the eight person-centred categories (Table 1). This was labelled the 'PCC percentage' variable. For example, a participant who provided 6 *dementia-related* attributions, 2 *likes-dislikes* and 2 *surface thoughts* would receive a score of 40%. This percentage score was used in preference to the raw number of person-centred attributions because there was considerable variation across participants in terms of the total number of attributions gathered from the interview. Much of

this variation appeared to be due to factors irrelevant to how person-centred the participant was, such as how talkative they were and what behaviour they chose to discuss. The percentage score provides a measure of the extent to which person-centred or dementia-related attributions dominated the participant's efforts to understand the behaviour, regardless of how talkative they were or what behaviours they had chosen for discussion. A higher percentage of person-centred attributions was taken as evidence that the participant was more person-centred in their efforts to understand the behaviour.

To assess the reliability of the coding system, all interviews were coded separately by one of the authors and another person who had been trained to use the coding system but who was unaware of the aims and hypothesis of the research. A meeting was then held with both coders. Disagreements in the coding were highlighted in this meeting, and, through discussion, an agreed set of codes was achieved. This agreed set of codes was used to calculate the variables used in the analysis. The two individual sets of codes were used to calculate the inter-rater reliability of the coding system.

Results

Data preparation

All participants provided full data sets. Prior to any analysis, the data were checked for outliers and for whether they met the assumptions of parametric analysis. None of the variable distributions departed significantly from normal. Using a criterion of 3.29 standard deviations from the mean, there were no univariate outliers. Pairwise plots were checked for multivariate outliers, non-linearity and heteroscedasticity. One clear multivariate outlier was detected in the pairwise plots for the main analysis (i.e. BRCM and *PCC percentage*). The data from this individual were accordingly excluded from further analysis. On closer examination, the interview of this participant yielded very few attributions and this increased the probability that the *PCC percentage* score would not be sensitive to how person-centred

the participant was. Collinearity and casewise diagnostics for the multiple regression analyses were also checked.

Sample

Thus the final sample was 25 people. Demographic and dementia-related details about these are contained in Table 2. All were married to a person with dementia of the opposite gender; all were the primary carer for a person with dementia who needed substantial support in dealing with the activities of daily living; all were living with that person in the family home; all were White British; and all were over 65 years of age. Participants endorsed a mean of 22 items on the 37 items of the CHS, suggesting a relatively high rate of care needs for the sample as a whole.

[Table 2 about here]

Frequencies and reliability analysis

From the 25 interviews, 256 attributions were identified. The frequency of attributions falling into each of the nine codes is shown in Table 3, which also shows the percentage agreement between the two coders for that category. The major source of disagreement was whether a feeling or a thought counted as *surface* or *deep*. The variable entered into the analysis (*PCC percentage*) was the number of person-centred attributions expressed as a percentage of the total number of attributions. There were 95 agreements about *dementia-related* encodings, 156 agreements about the attribution belonging to a person-centred category (although coders did not necessarily agree about which person-centred category the attribution belonged to – see Table 3), and 5 disagreements (i.e. one coder classed the attribution as belonging to a person-centred category and the other classed it as *dementia-related*). Inter-rater reliability for this variable was high (kappa = .959).

[Table 3 about here]

[Table 4 about here]

Descriptive statistics and correlations

Descriptive statistics are shown in Table 4 and correlations are shown in Table 5. As hypothesised, more *continuity* was associated with a higher *PCC percentage* score (r=.653; 95% confidence intervals: .348 to.833; p<.001).

[Table 5 about here]

Multiple regression

BRCM scores declined with an increase in care demands on the *cognitive* and *behaviour* subscales of the CHS (Table 3). These two subscales also showed significant correlations with *PCC percentage* (Table 3). This raised the possibility that the association between the BRCM and *PCC percentage* was a spurious one due to their common association with these care needs. To evaluate this possibility further, a standard multiple regression analysis was carried out in which the outcome variable was *PCC percentage* and the predictor variables were the BRCM scores and the *behaviour* and *cognitive* subscales of the CHS. In the regression, the BRCM did not make a significant contribution to variance in *PCC percentage* (Table 6). The explanation that the correlation between the BRCM and *PCC percentage* is a spurious one due to their association with care needs cannot be ruled out.

[Table 6 about here]

Discussion

The hypothesis was supported by the findings. Those reporting more *continuity* on the BRCM reported a higher percentage of person-centred attributions. The findings are consistent with previous qualitative studies that have suggested a link between *continuity* and PCC in spouses providing care for someone with dementia (Chesla et al., 1994; Lewis, 1998; Murray & Livingstone, 1998; Walters et al., 2010). By using a larger sample and reducing

the subjectivity involved in data analysis, the mixed-methods approach used in this study provides more robust evidence to support the suggestion (Johnson & Onwuegbuzie, 2004).

This connection between *continuity* and PCC also seems plausible from a theoretical perspective. When the spouse experiences *continuity* (i.e. the other person and the relationship are continuations of what has gone before), presumably they carry on making sense of the person with dementia using many of the same methods that they used before the onset of the dementia. Unless the pre-dementia relationship was dysfunctional, the methods are likely to involve some effort to understand challenging care needs from the perspective of the person with dementia (e.g. an attempt to figure out the complex thoughts and feelings that may be influencing their behaviour – the *deep thought* and *deep feeling* codes) and to make use of their extensive knowledge of the individual characteristics, attributes and history of that person (e.g. the *personal history* and *personality* codes). By contrast, in *discontinuity* the person with dementia no longer feels like the same person and these longstanding ways of understanding them may seem less relevant. The carer is faced with the task of constructing a new identity for the person with dementia and finding new ways of understanding them. Because of the prominence of the dementia and its impact on their life, it may be that this construction focuses on the other as a person with dementia, and that, in attempting to understand challenging care needs, the carer overlooks the schemas used in the past in favour of a more generic understanding of how people are affected by dementia (cf. Villa & Riley, 2017).

The study also investigated an alternative explanation of the correlation between *continuity* and PCC, specifically that the link may be a spurious one because it may be more difficult to maintain *continuity* and a person-centred approach when faced with more challenging care needs. When the BRCM and the cognitive and behaviour subscales of the CHS were entered together as predictor variables in a multiple regression, the BRCM no

longer made a significant contribution to the variance in the *PCC percentage* score. Thus the possibility of the correlation being spurious because of both being related to care needs cannot be ruled out. This, of course, does not mean that this alternative explanation is correct, only that it cannot be eliminated as an explanation.

The findings were consistent with the suggestion that *continuity* is more difficult to maintain in the face of certain care needs. The BRCM was negatively correlated with the *behaviour* and *cognitive* subscales of the CHS (i.e. greater discontinuity was associated with higher behavioural and cognitive care needs), uncorrelated with the *instrumental ADL* subscale and positively correlated with the *basic ADL*. The negative correlation with *behaviour* is consistent with the finding reported by Poveda et al. (2017) that *continuity* (as measured by the BRCM) was associated with lower scores on the Neuropsychiatric Inventory (which measures such things as disinhibition and agitation). Poveda et al. also reported that the BRCM was not correlated with a measure of social cognition skills. Superficially, this seems inconsistent with the negative correlation between the BRCM and the *cognitive* subscale of the CHS observed in this study. However, the content validity of the subscales of the CHS is questionable. The *behaviour* subscale includes some items that would more usually be considered cognitive issues (e.g. 'losing things' and 'leaving tasks uncompleted') and the *cognitive* subscale includes items that would normally be considered behavioural issues (e.g. 'changes in personality' and 'agitation'). The link between *relationship continuity-discontinuity* and different categories of care need merits further investigation with a more extensive range of measures of established validity.

Previous research concerning the attributions of paid and family carers about the care needs of people with dementia has reported that differences in attributions are associated with variation in both the emotional and coping responses of carers to those needs (e.g. Chen, Clayton, & Chodosh, 2017; Williamson et al., 2015). Most of these studies have used the

standard categories of attribution theory (i.e. internal-external, controllable-uncontrollable, personal-universal and stable-unstable). However, the attributional differences evident in the present study might also be linked with different emotional and coping responses. In qualitative studies of *continuity-discontinuity* in acquired brain injury (Bodley-Scott & Riley, 2015; Villa & Riley, 2017), it has been suggested that *continuity* enables the carer to manage challenging care needs more effectively because the carer is able to draw on a broader and richer range of explanations (e.g. those involving the past personal history of the person with the injury). By contrast, *discontinuity* appears to be associated with reliance on medical explanations and on professional advice about how to deal with the needs. Lacking a fuller understanding of the needs and lacking confidence in one's own abilities to manage the needs also appeared to be associated with a sense of bewilderment and helplessness. A lack of confidence about dealing with challenging behavioural needs has been reported to be associated with increased stress in family carers in dementia (e.g. Kuo, Huang, Hsu, & Yea-Ing, 2014). Further research is merited into the impact of the attributions observed in this study on the emotional response of family carers to challenging care needs and on their attempts to manage those needs.

Some limitations of the study should be noted. The sample was self-selected and so it is unclear how representative it is of the population of carers. The sample was also relatively small and exclusion of one data set meant it did not meet the power requirements. Given the magnitude of the correlations, this did not impact on the correlation analysis but a larger sample would have provided a more robust evaluation of whether the correlation between the BRCM and person-centred variable was due to the association of both to the level of behavioural and cognitive care needs. There was variation in respect of the care needs that participants chose to discuss in the interview. This is likely to have caused some confounding because certain types of caring need may be more likely to be understood using

certain categories of attribution. Finally, the design of the study precludes any causal conclusions about whether *continuity-discontinuity* has an impact on attributions. The alternative explanation of the association between continuity and PCC (i.e. that both stem from the presence of certain kinds of care need) could not be eliminated. There may also be other unmeasured variables that explain the association.

Given the ethical value of PCC and its impact on the well-being of the person with dementia and the carer, it is important to understand more about PCC in the context of family members caring at home for someone with dementia. Such understanding will help in the development of interventions to support family carers in delivering PCC. The present study suggests that a relational perspective may be of value in furthering our understanding of this issue. Specifically, *relationship continuity-discontinuity* may provide a useful framework for future research in this area, and the possibility of supporting PCC through enhancing the experience of *continuity* merits investigation.

Disclosure of interest

The authors report no conflict of interest.

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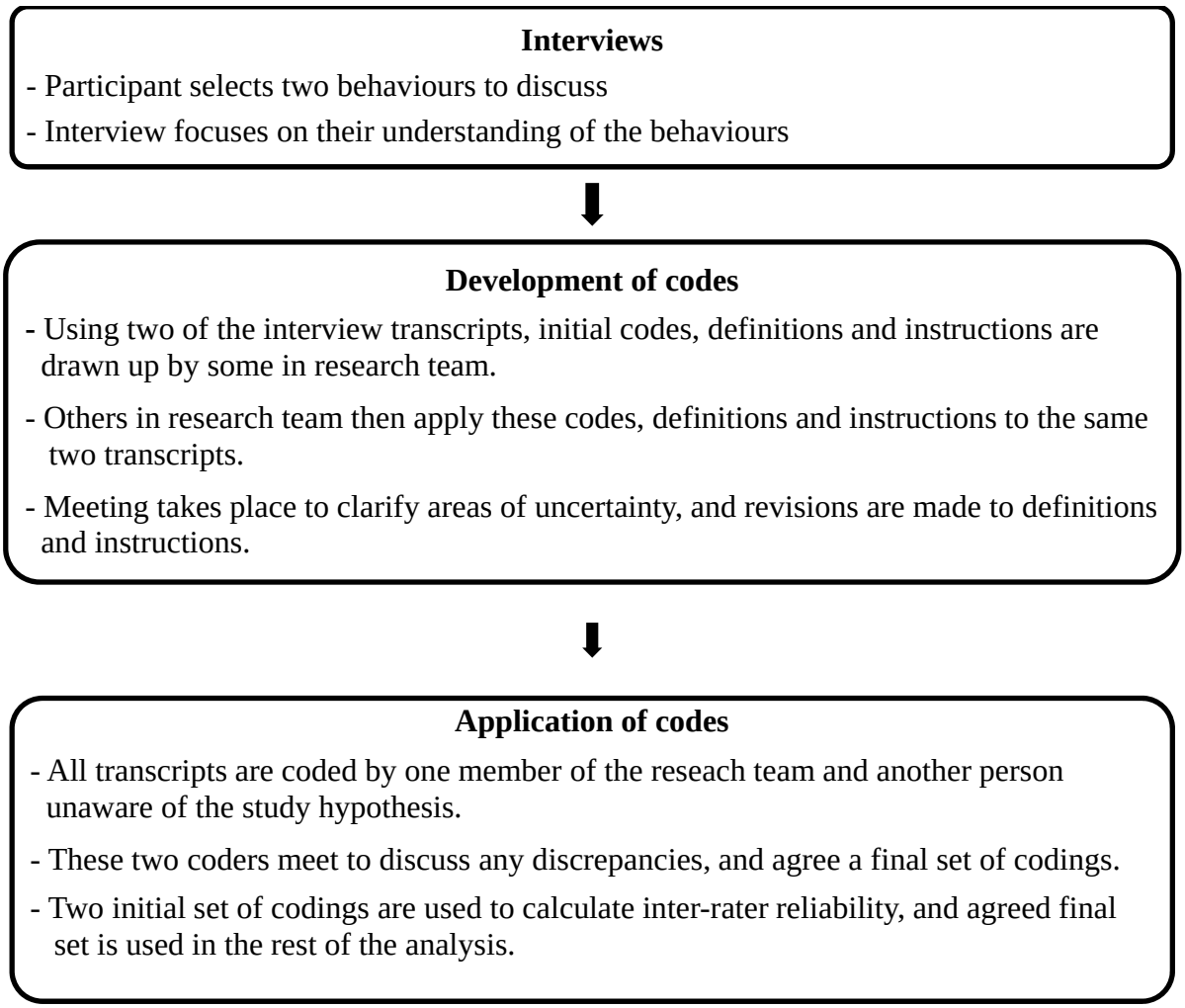

Figure 1: Derivation of the measure of person-centred care

Table 1

Definitions and examples of attributional codes

Coders were given the following definitions, along with some fictional examples of the category. Illustrative examples from the actual interviews are given below for each category.

1. **Dementia-related**: Understanding/management is influenced by beliefs about disabilities in language, cognition, physical or social functioning arising from the dementia. Include also any examples where the participant refers to 'dementia' generally.
Example: Participant is discussing his wife's habit of moving things around the house so that he cannot find them, and is explaining why he no longer tries to reason with her about this: "If I say to her 'please leave it where it is', there is no way she is going to remember that instruction…She can't cope with really any, very little in terms of communication. She speaks, she speaks, but she doesn't converse …It's not going to sink in, it's not going to stay there in her mind."

2. Personal history: Understanding/management is influenced by consideration of events or circumstances that happened to the person with dementia before the onset of the dementia. Include previous jobs, activities, achievements, major life events etc.
Example: Participant is explaining how he tries to distract his wife from endlessly pacing about the house: "In the nicer weather, I can say 'Right, I need to have a walk around the garden, see what needs watering' or something like that, and she quite happily will come around with me, sit and watch. I mean at one time she would've done job herself because she loved the garden, but she is happy enough to come sit outside and watch what's going on. That is another form of distraction because she is looking at something she'd loved doing or used to like doing."

3. Current events, activities and environment: Understanding/management is influenced by consideration of events that have taken place since the onset of the dementia; and/or features of the current social or physical environment in which the person with dementia finds themselves; and/or current activities.
Example: Participant is reflecting on his wife's frequent requests to go shopping to buy mints, and relates this to a cough she had the previous year: "She had been struggling with a cough. The cough had been much worse….[Taking a mint] doesn't work too much but it works a bit; but she's got this in her head now that a mint will cure her cough … as soon as she goes [mimics a slight clearing of throat] 'I want a mint'. Slightest cough- 'I want a mint'. And she wants to go to the shop for cough sweets - forever wanting to go." [Also coded as an instance of 'surface thought']

4. **Pre-dementia personality:** Understanding/management is influenced by the carer's beliefs about the lifelong pre-dementia personality of the person with dementia. Personality refers to general patterns of behaviour, thoughts and feelings that characterize the individual (e.g. being fussy, outgoing, ambitious). The evidence needs to be clear that the carer is thinking about the person's long-term personality, and not characteristics that have only emerged since the onset of the dementia.
Example: Participant is discussing her husband's lack of co-operation in the daily routine: "But he always wanted his own way. But then he did it in a different way. He kept on and on at you until in the end you gave in. If he wanted a new car, he just kept taking me to garages, to look at cars, and in the end, it was easier to say – 'have a new car'"

5. **Likes and dislikes:** The carer has considered the likes and dislikes of the person with dementia in their understanding/management.
Example: Participant is discussing his wife's wandering and how an incident with paid carers caused a problem: "And they put their hands upon her to try to, and no of course the reaction. It's always best not to put your hands on her. If she puts her hands out to you, that is fine. That [carers putting hands on her] happened in the home as well as outside. And so she reacted to that…. Don't try to embrace her or make any contact, because she'll react to it."

Thoughts: In their efforts to understand/manage the situation, the carer has considered what are/might be the thoughts of the person with dementia. Thoughts include appraisals and interpretations of the situation/strategy, and goals and intentions. References to cognitive states due to neurological impairment should be included under 'neurological impairments', and not as 'thoughts' (e.g. references to being 'confused' or 'forgetful').

6. **Surface thoughts**: Code as surface thought when the reference is vague; does not refer to specific thoughts that the person with dementia may have; and did not require the participant to take the perspective of the other person and think about what they are thinking (e.g. 'I suppose it's just the way he thinks about these things.').
Example: Participant is explaining why he does not raise his voice when dealing with repetitive questioning: "If I tend to raise my voice she'll tell me 'don't shout'. I'm not shouting I might be speaking a little bit stronger but certainly not shouting. But in [names]'s mind it's an affront to her personality."

7. **Deep thoughts**: Code as deep thought when the reference is to specific thoughts that the person with dementia has and there is evidence that the carer has given some thought to what the other person is thinking (i.e. that the participant has engaged in theory of mind activity). You should code as 'surface', instances where the participant's statements are just repeating what the person with dementia has said about what they are thinking.
Example: Participant is reflecting on why his wife asked repetitive questions about the time: "In the days when [name] was well and busy, she was involved in bringing up the lads…and she had to make do and mend and do a lot things, which she enjoyed doing. But she was always sort of working to the clock: ' I must do this before I go for the lads' and then, all this, like people do now, and I think that is sort of subconsciously timetabled, that's she's gone back in time, looking at the clock thinking 'it's quarter past three, I must go and do such and such'. It's like [name] thinking that she does all the washing and all the ironing and all the cooking. I think it's a similar thing." [Also coded as instance of 'personal history']

Feelings: In their efforts to understand/manage the situation, the carer has considered the feelings, mood or emotions of the person with dementia (both their feelings relating to the situation that triggers the challenging behaviour and their possible feelings should a particular coping strategy be used by the carer).

8. Surface feelings: Code as surface feeling if the reference is vague; does not refer to specific feelings that the person with dementia may have; and did not require the participant to take the perspective of the other person and think about what they are feeling (e.g. 'It's just mood swings.').
Example: Participant is explaining why he prefers persuasion to giving orders to deal with his wife's reluctance to engage in activities: "There are times in her day when if I do come on a bit strong and try to insist, she will get quite emotional and she will tend to lose her

temper a little bit."

9. Deep feelings: Code as deep feeling when the reference is to specific feelings and there is evidence that the participant has given some thought to what the other person is feeling (i.e. that the participant has engaged in theory of mind activity). You should code as 'surface', instances where the participant's statements are just repeating what the person with dementia has said about what they are feeling.
Example: Participant is reflecting on his wife's repetitive questioning: "And this business about asking for the mother and sometimes it's the father, and very often she thinks that I'm father, you know. I personally think it's the sense of security from the past when everything, I mean we all think our childhood was rosy and it was sunshine you know. And I think it is a throwback to that, it is the sense of security… And I think it's a sort of throwback to when the days were, when you were looked after."

Table 2

Demographic and dementia-related information (N=25)

Demographic/dementia-related variable	
Gender	12 males 13 females
Length of relationship	Mean = 48 years; SD = 14; range = 20 to 75
Type of dementia	Alzheimers = 12 vascular = 6 mixed = 4 fronto-temporal = 2 Lewy body = 1
Time since diagnosis	Mean = 3.4 years; SD = 1.9; range = 0.8 to 7.5
CHS total	Mean = 22; SD = 4.2; range = 11-29; possible range = 0-37

Table 3

Frequencies and percentage agreement for attributional categories

Category	Frequency	Percentage agreement
Dementia-related	96	96%
Personal history	12	85%
Current events, activities and environment	14	80%
Pre-dementia personality	7	63%
Likes and dislikes	16	72%
Surface thoughts	10	38%
Deep thoughts	19	65%
Surface feelings	63	65%
Deep feelings	19	35%
Total	256	

Frequency = number of occasions on which the code was used across all transcripts in the coding agreed by both raters
Percentage agreement = (number of occasions on which both raters agreed on the use of the code x 100) / total number of occasions on which the code was used by both raters

Table 4

Descriptive statistics

	Mean	Standard deviation	Possible range	Actual range
BRCM	62.0	20.6	23-115	29-101
CHS Behaviour	6.1	2.8	0-12	1-10
CHS Cognitive	6.4	1.4	0-9	3-9
CHS BADL	4.2	2.8	0-9	0-9
CHS IADL	5.3	1.5	0-7	1-7
CHS Total	22.0	4.2	0-37	11-29
PCC percentage	60.7	17.2	0-100	25-89

BRCM = Birmingham Relationship Continuity Measure; CHS = Caregiver Hassles Scale; BADL = Basic Activities of Daily Living; IADL = Instrumental Activities of Daily Living
PCC percentage: Percentage of total attributions that were person-centred

Table 5

Correlations

	BRCM	*PCC percentage*	CHS Behaviour	CHS Cognitive	CHS BADL
PCC percentage	.653* p=.010				
CHS Behaviour	-.722** p<.001	-.535* p=.006			
CHS Cognitive	-.498* p=.011	-.421* p=.036	.197 .346		
CHS BADL	.443* p=.026	.371 p=.068	-.552** .004	-.042 .844	
CHS IADL	-.081 p=.700	.042 p=.843	-.103 .625	.325 .113	.612** .001

BRCM = Birmingham Relationship Continuity Measure; CHS = Caregiver Hassles Scale; BADL = Basic Activities of Daily Living; IADL = Instrumental Activities of Daily Living
PCC percentage: Percentage of total attributions that were person-centred
* p<.05; ** p<.01

Table 6

Multiple regression

	Standardised coefficient	t-value	p-value	Zero-order correlation	Part correlation
CHS Behaviour	-.192	-.794	.436	-.535	-.128
CHS Cognitive	-.170	-.879	.389	-.421	-.142
BRCM	.429	1.570	.131	.653	.253

BRCM = Birmingham Relationship Continuity Measure; CHS = Caregiver Hassles Scale; Outcome variable: Percentage of total attributions that were person-centred